

The Social Determinants of Health and the Hierarchies of Knowledge

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Introduction: A Change in Perspective

From the perspective of social scientists who are engaged in the study of the social dimensions of health and disease, the report *Closing the Gap in a Generation: Health Equity Through Action on the Social Determinants of Health* stands out as very good news. Whether or not social scientists should be credited for their efforts towards promoting that sort of consciousness among health professionals and policy makers, the document clearly shows that views, goals, and even some methods of the social sciences are now currency at the higher levels of leadership in international health.

The report does more than acknowledge the importance of the social dimensions of health. It accurately details the critical aspects behind inequities in their very materiality and their diversity throughout the world: birth and childhood conditions; living environment; work, access to work, work safety, stability; systems and devices for social protection and health care. It also presents detailed strategies to mitigate the effects of inequities—by acting upon politics and economics at the local, global and intermediate levels, and by targeting the inequities directly related to gender, access to resources, to power, and to knowledge. Some of the statements risk looking like a wish-list of goodness embedded with a naïveté about a world that constantly re-asserts the human capacity to produce dreadful politics with devastating effects and avoidable tragedies.

Among social scientists, this report is likely to elicit a two-fold approach. First, there is appraisal and raised expectations about its potential impact. Guidelines for intervention coming from the World Health Organization are more likely to have a significant impact than the ones social scientists produce from their academic chairs or development agencies. It may also be the case

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that the historical moment for sustained global action has come; that does not depend on the World Health Organization alone. An optimistic view of the recent changes in economics and politics may see them as a sign that the future will bring a reduction in the ill-health effects of the neo-liberal economics, structural adjustments and war prone politics that have abounded in recent decades.

Second, there is reflection upon the implications of bringing the social determinants of disease, social knowledge and expertise of social scientists from the rear to the fore of health assessments. Does this imply turning upside-down the hierarchies established in health programmes, even among the multidisciplinary teams that were conceived as a site of plural conviviality of views?

There are certain examples from the past when social knowledge was called to the centre of action. The AIDS epidemic was one of them—one I got to witness from a close perspective during the late 1980s and early 90s in Rio de Janeiro.¹ This was a time when the interventions and messages of the World Health Organization's Global Programme on AIDS (GPA) strongly influenced the social responses to the epidemic, which, in turn, influenced state policies over the course of the years and matured into the quasi-legendary "Brazilian Responses to AIDS."² In this chapter I will analyse that case in order to support what I see as the argument of this volume: the relevance of social knowledge and the need for global action on health.

Hierarchies of Knowledge: The Biomedical, the Cultural and the Social

In the present report, the World Health Organization gives priority to analysing the social determinants of health and how they materialise in inequities. This

¹ The full account is included in Cristiana Bastos, *Global Responses to AIDS: Science in emergency* (Bloomington: Indiana University Press, 1999).

² For this discussion, see João Biehl, "The Activists State: Global Pharmaceuticals, AIDS and Citizenship in Brazil", *Social Text* 22, no 3, 2004, 105–32; A. Berkman, J. Garcia, M. Muñoz-Laboy, V. Paiva, and R. Parker, "A Critical Analysis of the Brazilian Response to HIV/AIDS: Lessons Learned for Controlling and Mitigating the Epidemic in Developing Countries", *American Journal of Public Health* 95, no 7, 2005, 1162–72; Jane Galvão, "Brazil and Access to HIV/AIDS Drugs: A Question of Human Rights and Public Health" *American Journal of Public Health* 95, no 7, 2005, 1110–16; Maj-Lis Foller, "Civil Society and HIV/AIDS in Brazil, in *No Name Fever: AIDS in the Age of Globalization*, ed. M. L. Foller and H. Thorn (Goteborg: Studentlitteratur, 2005) pp. xx–xx; Maj-Lis Foller and Hakan Thorn, eds., *The Politics of AIDS: Globalization, the State and Society* (New York: Palgrave, 2008), particularly chapters by Bastos, "From Global to Local and Back to Global: The Articulation of Knowledge, Politics and Assistance in Brazil", pp. 225–41, by Terto and García, "Mechanisms of Representation and Coordination of the Brazilian AIDS Responses: A Perspective from Civil Society", 242–54, and by Thorn and Foller, "Governing AIDS: Globalization, the State and Civil Society", 277–98.

means that here social knowledge is not considered a supplement, a complement, or an ornament of biomedical knowledge. This goes against the worldwide routine which takes biomedicine as the ultimate source of knowledge about health and the one which shapes health policies. The fact that the World Health Organization report brings first what generally comes last—social knowledge—should be reason for applause and examination. It should also be expected that on the ground, such recommendations may clash with established practices, perhaps within the World Health Organisation itself.

Before going on, I would like to emphasise that addressing social variables first does not mean putting biomedicine last, or removing it from the picture.³ Addressing social variables upfront implies more than just referring to or targeting the social constraints and inequities in access to healthcare; it also implies understanding that not only biomedical practices but biomedical knowledge is socially situated as well.

Biomedicine, either depicted as the “legitimate”, “modern”, or “scientific” medicine, or otherwise as the “hegemonic”, “dominant”, or “western-based” tool of colonisers and the colonised minds, does not exist independently of the social conditions that create the inequities in access to healthcare, or of social relations that also include the exercise of power and of economic interests. Its universal orientation co-exists with the fact that it is mediated by cultural practices, and that during colonialism, those practices mostly coincided with the interests of the colonisers, or of the groups that endorsed the interests of the colonisers; and that, beyond colonialism, those cultural practices often match class-based, caste-based, gender-based or ethnic-based interests. The contradictions and tensions that emerge in those situations have been subject to extensive documentation and rich academic debates. Sometimes, the dualistic opposition “local knowledge” vs “biomedical knowledge” oversimplifies the picture: local knowledge, too, may mediate private interests, and western-biomedical knowledge may be a local development in non-western places.⁴

³ The most often referred to, recent, and tragic example is provided by South African leaders’ generalized suspicion regarding biomedical approaches to AIDS. What may have started with a wish to acknowledge the importance of history, colonialism and social inequalities in the prevalence of disease ended as a sort of HIV-denialism, epitomised by President Mbeki’s famous address to the AIDS conference and the politics of delaying the use of ARVs. Sociologist Didier Fassin (*When Bodies Remember: Experiences and Politics of AIDS in South Africa* [Berkeley: University of California Press, 2007]) makes interesting points about the ways colonial abuse is processed as embodied knowledge. A comprehensive and long ranging overview is given by Randall Packard, “The History of the Social Determinants of Health in Africa”, in *History of the Social Determinants of Health: Global Histories, Contemporary Debates*, ed. Harold Cook, Sanjoy Bhattacharya and Anne Hardy (Hyderabad: Orient Longman, 2009), 42–77.

⁴ Physicians of international health who are also anthropologists, like Paul Farmer and Jim Kim, have made that point very clear using their own experience in Haiti, Peru and Africa with drugs for AIDS and Multi-resistant TB (e.g., Paul Farmer, *Infections and Inequalities*,

A commitment to human rights and the ability to detect extreme inequalities associated with gender, age, race, class, place, may serve as a device to prevent the ways in which inequalities may lie hidden under the flag of cultural relativism. Historians, physicians and anthropologists with hands-on experience in matters of global health have gone beyond this; they have also gone beyond the boundaries and limitations of the concepts of “medical systems” and of “resistance”. Instead, there is now a growing understanding that people combine elements from different traditions and streams of knowledge, including biomedicine, in order to face specific situations. Those arrangements may change through time and according to particular goals. It should be stressed that the constraints in such scenarios reveal inequities in power, status and access to resources, food and knowledge. These constraints determine the rules of interaction between health care delivery and access to health. Biomedicine stands at the confluence of those encounters, itself shaped asymmetrically. In these circumstances, the *sine qua non* should be to address social variables first, for a meaningful approach to global health issues.

When Social Knowledge Comes First: Notes from the AIDS Epidemic

There are times when social knowledge is brought from the periphery to the centre of thinking and action. This happens when there are signs that biomedicine alone cannot map the complexities of a health problem and that the behavioural, social and cultural elements have direct implications in its very definition.

The AIDS epidemic was one of those occasions. In the 1980s, and into the 1990s, there was a widely shared understanding that any consistent action against AIDS required the inclusion of some sort of social knowledge. While waiting for a true rescue from the epidemic, one that should come from the core of biomedicine—all attention focused on virology—those involved in AIDS work paid more attention than usual to what social knowledge might contribute.

But what sort of attention was that: the acknowledgement of an extra element at the end of a chain of explanatory variables, or a truly primary focus on the

Berkeley: University of California Press, 1999). Historians have also shown that people have selectively used elements of biomedicine in combination with their own traditional devices, as is well demonstrated for smallpox immunisation in India—e.g., Sanjoy Bhattacharya, Mark Harrison, and Michael Worboys, *Fractured States: Smallpox, Public Health and Vaccination Policy in British India 1800–1947* (New Delhi: Orient Longman, 2005); Sanjoy Bhattacharya, *Expunging Variola: The Control and Eradication of Smallpox in India, 1947–1977* (New Delhi, Orient Longman, 2006); Paul Greenough, “Asian Intra-Household Survival Logics: The ‘ShenTe’ and ‘Shui Ta’ Options”, in *History of the Social Determinants of Health: Global Histories, Contemporary Debates*, ed. Harold Cook, Sanjoy Bhattacharya and Anne Hardy, (Hyderabad: Orient Longman, 2009), 27–41.

social? For most of those involved in including social aspects, this merely meant adding a new element, presumed to come at the end of a hierarchical chain of knowledge-makers helping to interpret the new epidemic. Along that chain, virologists came first; then immunologists and specialists in infectious disease, then clinicians, epidemiologists, and only after these, the social scientists. Virologists defined what was at stake—HIV infection affecting the immune system and making the body unusually vulnerable to normally harmless infections—and immunologists went along. Clinicians observed and treated diseased bodies accordingly, that is, adjusting the available weaponry to the targets. Epidemiologists counted and calculated numbers of infected bodies, ill or asymptomatic, around the globe, in each locale, within each population, and tried to track the paths of transmission. And finally, social scientists joined in to assess, interpret and explain why people had the behaviours that virologists, clinicians, and epidemiologists together reported to be the routes of transmission. Such hierarchy can be depicted this way:

basic science > clinic > epidemiology > social knowledge
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Social researchers were called in to assess why people had the behaviours defined above, how they had them, how many times they had them, how many others were affected by them, and what could be done to prevent them from acting that way. In the end, and up until today, social scientists were invited to fill in the gaps left between models and actual behaviour—why did people infect themselves despite knowing how not to get infected? Paradoxically, social scientists had to supply answers for a “social” dimension that was all but what they knew as “social”: it was actually about the repeated behaviour of ideal individuals supposedly acting on the basis of free choice, supposedly conscious agents of their own infections and conditions—or, the idealised, constraint-free, neoliberal decision-making *homo economicus*.

Some social scientists acted accordingly, doing their best to count and assess the behaviours connected to the epidemic as they were framed in the higher levels of the knowledge chain, supported on the assumption that everyone is free to make choices about their own inputs and outputs of bodily fluids, be they semen, blood or milk. Many social inquirers sought and still search for “traditional” and “exotic” sexual behaviour or bloody (literally and metaphorically) ritual behaviour. Or they seek for reasons why people do not use the thousands of condoms distributed by AID agencies, or why they simply don’t say no to sex with infected partners, or to sex altogether.

Others social scientists ventured to address the complexities involved in the very acts of sex, breast feeding, injection and other incidents of exchanging bodily fluids from one individual body to another—but that do not really involve the agency and free choice of the one individual whose body is the subject of the transaction of fluids and viruses, and whose self is in a complex

web of power relations: the woman who cannot deny sex to the man she is married to, or cannot demand to know his HIV status, otherwise risking to be killed, beaten, or losing her social persona and her means of survival; the woman who cannot deny her breast milk to her infants, who will otherwise die; the sex workers who exist within a web of economic and political constraints; the politicians whose worldviews make it easier to see AIDS as a foreign invention rather than address it.

Those issues can only be addressed if social variables come up front, not at the tail of a chain of biomedical reasoning where behaviour appears in a free will model that does not account for the wider mechanisms of power and notions of disempowerment and empowerment. Social disciplines, including the social epidemiology that developed in pre-AIDS Latin America, were well familiar with this. And yet, with all the calling for social understanding and for multidisciplinary teams, the knowledge of social epidemiologists did not emerge as a primary tool to face the new epidemic. Their knowledge had a peripheral status within a hierarchy of disciplines that was conditioned by power, legitimised by history and made routine via culture.⁵

Meanwhile, the primacy of the social was being spread via other channels: through the action of WHO itself, and most visibly so during the mandate of Jonathan Mann at the Global Programme on AIDS (GPA). From early on his team sent the message across the world that the social, economic and political dimensions of AIDS were central not only to understanding the epidemic but to act upon it. While most everyone was counting sex acts and condom use and asking why people weren't acting according to the information they had about AIDS transmission, this group insisted that as long as gender asymmetries remained there was little chance of stopping the transmission of AIDS to women. They focused on empowerment, on civil society action, on civil rights, and other elements that were not traditionally a part of the core messages in international health. When no longer head of the GPA but still part of the leadership in the global fight against AIDS, Mann dedicated the report *AIDS in the World* to someone who epitomised the involvement of civil society not only regarding action against AIDS but also on knowledge making about

⁵ Only a few of the early works on the spread of AIDS made serious attempts to reverse that order and bring social variables first, which equated, for instance, establishing connections between the epidemic in Africa and the structures of asymmetry, the effects of colonialism, mining, wars, displacements, forced migration, and rapid urbanisation. Early and visionary examples are the articles by Randall Packard and Paul Epstein "Epidemiologists, Social Scientists, and the Structure of Medical Research in Africa", *Social Science & Medicine* 33, no. 7, 1991, 771–82, and by Brooke Grundfest Schoepf, "Ethical, Methodological and Political Issues of AIDS Research in Central Africa", *Social Science & Medicine* 33, no. 7, 1991, 749–64.

AIDS: the Brazilian activist Herbert Daniel.⁶ The intense, direct connection between global and local, as represented in that duo in the Amsterdam-based International Conference on AIDS in 1992,⁷ was more than a meaningful encounter and a tribute to activism. The analysis that follows will argue that this connection was at the root of what matured into the famous Brazilian responses to AIDS.

The Brazilian Experience and the Importance of a Global Agenda

In the first decade of AIDS, Brazil was considered a place where the epidemic might explode like wildfire. Stereotypes about Brazilian sexuality helped strengthen those expectations—a population perceived as hypersexual was expected to breed the highest transmission rates. The World Health Organization, donor agencies, scientists and public health specialists around the world paid attention to the epidemic in Brazil, monitored it, supplied assistance, funds, technical expertise and anxiety.

But what followed was different. Although the epidemic tragically and directly affected many tens of thousands in Brazil, and indirectly the entire society, its growth did not follow the worst possible scenario. Instead, two decades later, Brazil arose as the poster-country in matters of taming the epidemic.⁸ The reasons for that have been analysed extensively. In the late 1990s and 2000s the government coordinated programmes in the areas of both prevention and treatment that involved different sectors of society, with the technical assistance of NGOs and a wide basis of support. Treatment provided in the public system included the free distribution of otherwise expensive anti-retroviral drugs (ARVs).⁹ Politicians capitalised on the impact and positive effect of that programme. Whenever they considered suspending the distribution of ARVs due to its costs, they reconsidered and kept it for the sake of political gains.

Politicians once involved in the decision making processes that led to the inclusion of ARVs in the government bill, credit the accomplishment to their constituencies: “Brazil has a strong civil society”, says president Cardoso, who was in office during the arm-bending situation regarding the prices of ARVs

⁶ Jonathan Mann, Daniel Tarantola, and Thomas Netter, eds., *AIDS in the World: A Global Report* (Cambridge, MA: Harvard University Press, 1992).

⁷ The conference was relocated from Cambridge, Massachusetts, to Amsterdam, Netherlands so that people with AIDS could travel freely to the conference location (the US had objections to issuing entry visas to people with HIV) and participate fully in the conference work.

⁸ Berkman et al., “A Critical Analysis of the Brazilian Response to HIV/AIDS”.

⁹ Jane Galvão “A política brasileira de distribuição de medicamentos anti-retrovirais: privilégio ou um direito?” *Cadernos de Saúde Pública* 18, no 1, 2002, 213–19; Galvão, “Brazil and Access to HIV/AIDS Drugs”.

and the costs of patents—and who had also been responsible for signing the treaty on intellectual property which obliged Brazil to pay for the ARVs patents.

My analysis is slightly different, and it will bring us back to one of the items of the document we have on the table: *the priority given to social factors and global action*.

Brazilian civil society is indeed vocal and strong, but that alone does not explain the development and success of the Brazilian AIDS programme; nor was Brazilian civil society that strong and vocal in the early years of the epidemic. Nor was there a converging action towards addressing AIDS in a multi-front way (except perhaps in the city of São Paulo). Even though some of the older AIDS organizations aimed to be multidisciplinary—like ABIA, whose very name was *Associação Brasileira Interdisciplinar de AIDS*—what I witnessed in the late 1980s and early 1990s was a fragmented world where the various disciplines worked in different tracks and along with their own international networks.

The biomedical sector mobilised hierarchically around core knowledge about the virus, the segments of the virus, the behaviour of the segments of the virus, the responses of the elements of the virus to chemicals and potential medicines. Everything else, including clinical knowledge and epidemiology, was subordinate to that inner core. Social epidemiology, like the local clinical expertise developed in the context of tropical medicine and the treatment of infectious diseases, was temporarily put aside.

In this scenario, what was the role of social scientists? Interestingly enough, they were most likely to be involved either in research projects or civil rights actions that set them worlds apart from the constraints which affected epidemiologists, clinicians and bench scientists. Either based in university departments or in large NGOs that could hire them full time, social scientists seemed to be able to manoeuvre, theorise and intervene on a much wider scope than their counterparts in the biomedical sciences. Closely intertwined with the development sphere which had matured in Latin America, and marked by that style of intervention rather than by the community action and direct lobbying that characterised AIDS activism in the United States, social activists and social scientists in Brazil followed the lead of the World Health Organization Global Programme on AIDS quite well in bringing social variables upfront, and with that promoted empowerment, ability to intervene and ability to produce knowledge. This happened faster than in the biomedical sciences, whose international connections were slower to build up and led to more dependent research programmes, including in epidemiology.

In the end, this arrangement had a very unique outcome: the empowered civil society that the social scientists contributed to greatly, created a culture of AIDS experts which ended up executing the AIDS programme that came full circle, to be the height of efficiency. The importance of the AIDS NGOs was

crucial for the development of what ultimately became a mature AIDS culture and a model programme that now provides expertise to many other countries in the world.

To make a long story very short, when in 1996 ARVs became available as the new, efficient and predictably expensive medicines for HIV, many around the world thought that those pills would help redrawing the line of the health divide—the one that separates the rich from the poor in most of the health issues, and the one that had temporarily been suspended from the picture due to the global dimensions of AIDS. Since Brazil is known for its dual health pattern, as if concentrating the world divide, most expectations were that here, too, the rich would buy their expensive pills and the poor would be deprived from them.

But things happened differently. Soon after, activists from São Paulo asked in court for the free delivery of ARVs to patients whose medical condition recommended so. The argument was that people were granted by the constitution with the right to live; not providing those medicines to those in need would equate to deny them their of constitutional rights.¹⁰

The activists won: the justice was sympathetic to the cause. At that time, and much as a result of the activists and social scientists public interventions, AIDS was seen in Brazil as a public issue that affected the entire society. The social and the public sphere came first: in theory, the state should be responsible for the well-being of its citizens. In practice, that implied—at least in that moment—that the state should provide ARVs to people with AIDS. The court decision opened a precedent, and providing ARVs in the public system became the norm.

That this was possible at a time when many politicians around the world were engaged in denying AIDS should be credited to a peculiar combination of factors, and above all, I argue, the local-global connection that brought together a common agenda for local activists and the WHO AIDS Programme with the emphasis on human rights. By the time ARVs became available as public treatment, there was no way back, even when the costs of the bill became unusually high. Providing ARVs for free was a central element in the applauded “Brazilian model”, considered the best accomplishment, by a single country, in controlling the AIDS epidemic. No politician would want to change that achievement.

¹⁰ Mário Scheffer, et al., *O remédio via justiça: um estudo sobre o acesso a novos medicamentos e exames em HIV/AIDS no Brasil por meio de ações judiciais* (Brasília: Ministério da Saúde, 2005); Galvão, “a política brasileira”; Galvão, “Brazil and Access to HIV/AIDS Drugs”; also, those views were expressed in personal communication by lawyer and AIDS rights advocate Áurea Abade, from GAPA-SP.

Concluding Remarks

The emphasis on human rights shared by WHO and Brazilian activists—as epitomised by the Jonathan Mann-Herbert Daniel proximity—was no ornament to a strictly medical response to the AIDS epidemic. GPA's stress on global action, human rights and empowerment was not a mere rhetorical segment flagged to the masses in the absence of adequate biomedical instruments. It was central to shape the materiality of some of the local responses that ended up acting rapidly and making full use of the biomedical instruments produced in the meantime.

In Brazil, the widespread understanding of the AIDS epidemic as a public issue—largely the result of social scientists and activists with the support of WHO—was crucial to influence the choices that made a dramatic difference in access to treatment and care and in matters of life and death, health and illness, well being and suffering.

That those choices could be made at all should be related to another set of factors, also peculiar of Brazil. This is a place where biomedicine is closely intertwined with nation-building, where sanitary movements of early twentieth century are at the centre of national iconography, and where public health was a successful instrument to expand the inner frontiers. The infrastructure was there: albeit depleted in many instances, there was a public system of health services matched by an ideal of a public sphere serving its citizens, one that provided the rational for choosing to place ARVs in the public system.¹¹

There was, however, a high cost for those choices. By having agreed with the principles of paying for the intellectual property in international trade (TRIPS), Brazil was bound to pay for the expensive patent rights that the pharmaceutical companies charged for the manufacturing of ARVs. The tension between the intellectual property rights owned by large corporations and the urge to produce the medicines at lower costs earned worldwide attention.¹² Technically, Brazil was able to manufacture the medicines at lower costs. The arm-bending negotiations that emerged from that tension resulted on the lowering of costs.

The “Brazilian response to AIDS” combines a diversity of elements—biomedical issues like ARVs, economic issues like costs and prices, legal issues like patents, techno-science issues like manufacturing the molecules after reverse engineering in Brazilian laboratories, and political issues like the arm-bending with the World Trade Organization. That they were all brought

¹¹ Biehl finely analyses the implications and limitations of a model of distribution based on assumptions of “biomedical citizenship” (Biehl, “The Activist State”; João Biehl, *Will to Live: AIDS Therapies and the Politics of Survival* (Princeton, NJ: Princeton University Press, 2007).

¹² Oxfam-Great Britain, *Drug Companies vs. Brazil: The Threat to Public Health*. (Oxford: Oxfam, 2001).

together into a positive outcome could not have been possible without the development of a mature AIDS culture, which in turn evolved around the focus on the social dimensions of the epidemic.

Without the World Health Organization's emphasis on global action, support to local activism, and priority to the social and political dimensions of AIDS, Brazilian activism would probably not have gone as far in achievements as it did, nor would society be so ready to endorse the epidemic as a public issue when the time to make hard economic and legal choices came about. In other words, this is a clear example—and hopefully, one that should be followed by many others—of the impact of a globally sponsored emphasis on the social determinants of health.